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Greater Experience of Negative Non-Target Emotions by Patients with Neurodegenerative Diseases Is Related to Lower Emotional Well-Being in Caregivers

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Keywords

Non-target emotion · Subjective emotional experience · Caregiver well-being · Neurodegenerative disease · Frontotemporal dementia · Alzheimer's disease

Abstract

Background: Behavioral symptoms in patients with neurodegenerative diseases can be particularly challenging for caregivers. Previously, we reported that patients with frontotemporal dementia (FTD) and Alzheimer's disease (AD) experienced emotions that were atypical or incongruent with a given situation (i.e., non-target emotions). **Aim:** We tested the hypothesis that greater experience of non-target emotions by patients is associated with lower caregiver emotional well-being. **Methods:** 178 patients with FTD, AD, or other neurodegenerative diseases and 35 healthy individuals watched 3 films designed to induce amusement, sadness, and disgust, and then reported their emotions during the films. Caregivers of the patients reported their own emotional well-being on the Medical Outcomes Study 36-item Short-Form Health Survey. **Results:** In response to the amusement and sadness (but not disgust) films, greater experience of non-target emotions by patients was related to lower caregiver emotional well-being. These effects were specific to patients' experience of negative non-target emotions (i.e., not found for positive non-target emotions or for negative or positive target emotions). **Conclusion:** The findings reveal a previously unstudied patient behavior that is related to worse caregiver emotional well-being. Future research and clinical assessment may benefit from evaluating non-target emotions in patients.

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Introduction

Given the increasing prevalence of dementia and other forms of neurodegenerative diseases, caregiving is becoming an increasingly important consideration for a growing number of families [1]. Caring for a family member who is living with a debilitating, progressive disease can be highly burdensome, leading to declines in caregivers' emotional well-being along with a number of mental health problems such as depression and anxiety [2, 3]. Recent findings suggest that these kinds of caregiver mental health problems may lead to greater patient mortality [4]. Importantly, caregivers differ in the extent of their vulnerability to the negative effects of caregiving [5]. Thus, identifying the factors that influence this vulnerability will be extremely important for improving health outcomes for both caregivers and patients.

A significant body of research has suggested that behavioral symptoms in patients may be particularly challenging for caregivers, even more so than cognitive and functional symptoms [6, 7]. In our own work, we have found that neurodegenerative diseases can produce profound changes in patients' emotional behavior, including alterations in reactivity (generating emotional responses [8]), regulation (adjusting emotional responses [9]), and recognition (identifying emotions in others [10]). Importantly, we have found that deficits in patients' emotional functioning (i.e., less frequent use of visual avoidance of negative stimuli – a specific type of emotion dysregulation) are associated with adverse outcomes in caregivers (e.g., greater psychological distress [11]). In the present study, we examine the impact of deficits in patient *emotional reactivity* on caregiver well-being, with a particular focus on subjective emotional experience.

Alteration in Subjective Experience of Emotion in Neurodegenerative Diseases

The subjective experience of emotion is critical for adapting to life's challenges and opportunities and for a broad range of social behaviors [12, 13]. The “feelings” that accompany emotions provide valuable information that guide behaviors (e.g., approaching things that generate pleasant feelings), create links with memories of emotionally similar events, and inform conspecifics of preferences and likely future actions [14]. In neurodegenerative diseases, when a patient's emotional experiences are atypical or incongruent with a given situation (e.g., becoming angry in response to a caregiver's act of kindness), it can be confusing and frustrating for caregivers. Over time, these occurrences can erode the quality of the patient-caregiver relationship, which can have negative effects on caregiver and patient well-being [15].

Patients with neurodegenerative diseases including frontotemporal dementia (FTD) and Alzheimer's disease (AD) undergo atrophy in large-scale neural networks [16] that underlie various aspects of emotional processing, including the production of subjective emotional experience. For example, we found that patients with FTD experienced less disgust (the target emotion) when exposed to films that portrayed filth and contamination [8]. In a recent study, we found that patients with FTD and AD reported experiencing more atypical or non-target emotions than patients with other neurodegenerative diseases and healthy controls (HC). To illustrate this, patients in the study experienced anger in response to a slapstick comedy that primarily produced the target emotion of amusement in most viewers [17].

The Present Study

The present study examined the relationship between subjective experience of non-target emotions by patients with various forms of neurodegenerative diseases and emotional well-being in their caregivers. The patients self-rated their emotional experiences after watching 3 films designed to induce target emotions of amusement, sadness, and disgust. Caregiver emotional well-being and physical functioning (included as a control measure to

ensure that the observed effects did not extend to other non-emotional domains) were measured using the Medical Outcomes Study 36-item Short Form Health Survey (SF-36 [18]). We hypothesized that greater patient experience of non-target emotions is associated with lower caregiver emotional well-being.

Methods

Participants

Participants were recruited through the Memory and Aging Center at the University of California, San Francisco (UCSF), and included 178 patients with FTD, AD, or other neurodegenerative diseases (OND) that primarily impact motor functioning (e.g., corticobasal syndrome, progressive supranuclear palsy, and amyotrophic lateral sclerosis without frontotemporal degeneration), and their caregivers. Patients were diagnosed based on current consensus criteria [19–24]. Caregivers¹ were either spouses or domestic partners (84.8%), parents (0.6%), siblings (7.3%), adult children (6.2%), or friends (0.6%) who identified themselves as playing a primary role in providing care for the patient. Additionally, 35 neurologically HC and their spouses (82.9%), children (5.7%), or friends (11.4%) were recruited from the community. Demographic characteristics of all participants are shown in Table 1.

Procedure

After being assessed at UCSF, patients and caregivers came to the Berkeley Psychophysiology Laboratory for a comprehensive day-long assessment of emotional functioning [25].² Informed consent was obtained from both patients and caregivers upon their arrival. All procedures were approved by the Institutional Review Board of the University of California, Berkeley.

Patient Emotional Assessment. The present study focused on the part of the assessment in which participants (patients and controls) viewed 3 films (in a fixed order) that had been previously found to elicit 1 of 3 target emotions in neurologically healthy adults [17, 26, 27]: amusement (*I Love Lucy*), sadness (*The Champ*), and disgust (*Fear Factor*). Participants rested for 60 s before watching each film. Film lengths were between 87 and 106 s. After watching each film, participants answered the following questions³ regarding their experience while watching the film: (a) an open-ended question where they indicated the emotion they felt most strongly; (b) a valence question where they rated the valence of their overall experience (i.e., “good,” “neutral,” or “bad”); and (c) specific emotion questions where they rated their subjective experience of 10 emotions in a fixed order (i.e., affection, fear, amusement, anger, shame, disgust, embarrassment, enthusiasm, pride, and sadness) on a 3-point scale (0 = not at all; 1 = a little; 2 = a lot). The 10 emotions included 4 positively valenced emotions (affection, amusement, enthusiasm, pride) and 6 negatively valenced emotions (anger, disgust, embarrassment, fear, sadness, shame).

Caregiver Assessment.⁴ While patients completed the assessment of emotional functioning, caregivers completed the SF-36, which assessed their emotional well-being and physical functioning.

¹ Information regarding the relationship to the patient was missing for 1 caregiver. To ensure that the effects found in this study did not simply reflect differences in caregivers’ relationship to the patient (e.g., spousal caregivers had lower emotional well-being than non-spousal caregivers), we performed additional analyses similar to that for Table 4 that included spousal relationship as an additional covariate (1 = spousal; 0 = non-spousal). These analyses revealed similar results, with greater patient experience of negative non-target emotions in the amusement ($p = 0.03$) and sadness ($p = 0.04$) films associated with lower caregiver emotional well-being.

² In addition to the 3 films used in the present study, the assessments [25] included other stimuli and situations that produce emotional responses (e.g., sing a song), tasks where patients try to regulate their emotional responses, tasks involving emotion recognition, and a task where patients and caregivers have a 10-min unrehearsed conversation about an area of disagreement in their relationship.

³ The patients also answered other questions including how calm they were while watching the film and whether they remembered particular details about the film; these data are not reported here.

⁴ Caregivers also completed the Symptom Checklist-90-R (SCL-90-R) [28], which assesses 9 domains of psychopathology. Because the SCL-90-R does not assess physical functioning, we used the SF-36 for the present study.

Table 1. Demographic characteristics of caregivers and patients

	FTD (n = 96)	AD (n = 44)	OND (n = 38)	HC (n = 35)
Caregiver				
Sex	55 F; 41 M	27 F; 17 M	22 F; 16 M	19 F; 16 M
Age, years	60.53 (1.04)	60.52 (1.19)	62.95 (1.58)	63.03 (1.78)
Patient				
Sex	39 F; 57 M	21 F; 23 M	18 F; 20 M	21 F; 14 M
Age, years	63.39 (0.79)	62.16 (1.38)	66.66 (1.21)	66.91 (1.38)
Dementia severity: CDR-total	0.93 (0.06)	0.84 (0.06)	0.77 (0.10)	0 (0.00)
Dementia severity: CDR-box	4.96 (0.34)	4.27 (0.33)	4.73 (0.52)	0 (0.00)

Data are mean (SE) unless indicated otherwise. FTD, frontotemporal dementia; AD, Alzheimer's disease; OND, other neurodegenerative diseases; HC, healthy controls; CDR, Clinical Dementia Rating Scale; M, male; F, female.

Measures

Patient Subjective Emotional Experience. The 3 films were selected to elicit target emotions of amusement, sadness, and disgust. For the analyses, we created scores for: (a) positive non-target emotions and (b) negative non-target emotions by averaging the ratings of the remaining emotions in each category. For example, for the sadness film, the target emotion was sadness; the positive non-target emotion score was the averaged ratings for affection, amusement, enthusiasm, and pride; and the negative non-target emotion score was the averaged ratings for anger, disgust, embarrassment, fear, and shame.

Patient Dementia Severity. Clinicians at UCSF assessed patients' dementia severity using the Clinical Dementia Rating Scale (CDR [29]). Two CDR scores were obtained: total score (CDR-total; range = 0–3) and sum of boxes (CDR-box; range = 0–18); for both, higher scores indicate greater dementia severity. For HC, the CDR scores were coded as 0. In data analyses, we used CDR-box as a covariate because it provides potentially greater sensitivity (i.e., larger range) to variations in patient impairment.

Patient Emotion Rating Deficit. Self-report of emotional experiences may be compromised in patients with neurodegenerative diseases due to language dysfunction or difficulty in using rating scales [8, 17]. To account for this, we quantified inconsistencies between the valence of a participant's answers to the open-ended questions and the valence that the participant endorsed in the following question. For example, if the participant reported, "I felt sad" to the open-ended question but then reported that this feeling was "good" in the follow-up question, this would suggest problems in understanding the meaning of "sadness" or in rating the valence of emotional experience using the scale. The number of inconsistencies was calculated for each participant.

Caregiver Emotional Well-Being and Physical Functioning. Caregiver emotional well-being and physical functioning were assessed using the SF-36 [18], a self-report questionnaire assessing 8 health domains including emotional well-being (e.g., "Have you been a very nervous person?" "Have you felt downhearted and blue?" "Have you been a happy person?") and physical functioning (e.g., "Does your health now limit you in walking more than a mile?").⁵ For the complete list of items, see online supplementary Table 1 (for all online suppl. material, see www.karger.com/doi/10.1159/000481132).

Data Analyses

We examined the associations between patient experience of positive and negative non-target emotions (predictors) and caregiver emotional well-being and physical functioning (dependent variables). Based on

⁵ Other health domains assessed in SF-36 included: (a) role limitations due to physical health; (b) role limitations due to emotional problems; (c) energy/fatigue; (d) social functioning; (e) pain; and (f) general health.

previous research [17], we accounted for a set of covariates⁶ that may affect these key study variables, including: patient age, sex, disease status (i.e., patient vs. controls), dementia severity (CDR-box), and patient emotion rating deficit. Additionally, we included patient report of the target emotion as a covariate to account for individual differences in emotional reactivity [30].

Preliminary analyses included analyses of variance and Pearson correlations to examine between-group differences and correlations between the predictors and dependent variables. Primary analyses included multiple regressions conducted separately for each film, in which we entered covariates in the first step and patient experiences of positive and negative non-target emotions in the second step to predict either caregiver emotional well-being or physical functioning.

To rule out the possibility that the observed effects simply reflected diagnostic differences, we performed similar regression analyses replacing “disease status” and “dementia severity” covariates with 3 dummy variables (yes = 1; no = 0) for specific diagnosis: FTD, AD, and OND. Online supplementary Tables 3 and 4 present these results.

Results

Preliminary Analyses

Table 2 presents results for analyses of diagnostic group differences in the predictors and dependent variables. Results revealed significant group effects in caregiver emotional well-being ($F_{3, 209} = 8.10, p < 0.001$). Post hoc comparisons (Bonferroni-corrected) indicated that caregivers of FTD patients had significantly lower emotional well-being than partners of HC ($p < 0.001$). Caregivers of AD ($p = 0.067$) and OND ($p = 0.061$) patients also had lower emotional well-being than partners of HC at trend levels. As reported previously [17], results also revealed significant group effects in self-reported non-target emotions in all 3 films ($F > 4.25, p < 0.006$). Post hoc comparisons (Bonferroni-corrected) revealed that patients with FTD reported greater experience of negative non-target emotions in all 3 films and greater experience of positive non-target emotions in the amusement and disgust films, compared to at least 1 of the other 3 groups ($p < 0.05$). Patients with AD reported greater experience of positive non-target emotions than the OND and HC groups in the amusement and sadness films ($p < 0.05$; Table 2).

Table 3 presents the Pearson correlations between the predictors and dependent variables. These revealed that greater experience of positive and negative non-target emotions by patients in response to the amusement and sadness films was associated with lower caregiver emotional well-being (r values between -0.15 and -0.22 ; $p < 0.032$), but not physical functioning ($p > 0.186$). These effects were not found for the disgust film.

Patient Experience of Non-Target Emotions and Caregiver Emotional Well-Being

As shown in Table 4, after accounting for the covariates, greater experience of *negative* non-target emotions by patients in response to the amusement ($\beta = -0.17, t = 2.50, p = 0.01$) and sadness films ($\beta = -0.15, t = 2.05, p = 0.04$) was significantly associated with lower caregiver emotional well-being. This relationship was not found for the disgust film ($\beta = -0.08, t = 1.12, p = 0.26$). There were no significant relationships between patient experience of *positive* non-target emotions in response to any of the films and caregiver emotional well-being ($t < 0.67, p > 0.50$). Results from the additional regression analyses controlling for

⁶ To verify the selection of these covariates, we performed Pearson’s correlations and found that all covariates except emotion rating deficit and self-reported experience of target emotions were significantly correlated with caregiver emotional well-being ($p < 0.01$). In addition, all covariates except patient sex were significantly correlated with patient experience of either positive or negative non-target emotions in at least 1 of the 3 films ($p < 0.05$). These correlations are presented in online supplementary Table 2.

Table 2. Statistics for key study variables including predictor (patient) and dependent (caregiver) variables

	FTD	AD	OND	HC	<i>F</i>	<i>p</i>	Post hoc comparisons ^a
Caregiver							
Emotional well-being	69.52 (1.87)	75.93 (2.44)	75.47 (3.10)	85.71 (1.50)	8.10	<0.001	FTD<HC***, AD<HC [†] , OND<HC [†]
Physical functioning	85.84 (1.86)	88.64 (1.92)	86.71 (3.35)	88.69 (2.55)	0.39	0.76	
Patient							
<i>Amusement film</i>							
Positive non-target emotions	0.78 (0.07)	0.92 (0.09)	0.32 (0.07)	0.45 (0.08)	9.58	<0.001	FTD>OND***, FTD>HC*, AD>OND***, AD>HC**
Negative non-target emotions	0.24 (0.04)	0.09 (0.03)	0.07 (0.02)	0.11 (0.04)	4.36	0.005	FTD>AD [†] , FTD>OND*
<i>Sadness film</i>							
Positive non-target emotions	0.43 (0.05)	0.52 (0.07)	0.24 (0.05)	0.24 (0.04)	4.91	0.003	AD>OND*, AD>HC*
Negative non-target emotions	0.47 (0.05)	0.33 (0.07)	0.21 (0.05)	0.28 (0.06)	4.26	0.006	FTD>OND**
<i>Disgust film</i>							
Positive non-target emotions	0.37 (0.05)	0.25 (0.04)	0.08 (0.02)	0.15 (0.04)	6.78	<0.001	FTD>OND***, FTD>HC*
Negative non-target emotions	0.66 (0.06)	0.34 (0.07)	0.36 (0.07)	0.43 (0.07)	6.13	<0.001	FTD>AD**, FTD>OND*

Data are mean (SE). FTD, frontotemporal dementia; AD, Alzheimer's disease; OND, other neurodegenerative diseases; HC, healthy controls. [†] $p < 0.10$; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$. ^a Level of significance corrected using the Bonferroni method for multiple comparisons.

Table 3. Correlations between key study variables

	Caregiver	
	emotional well-being	physical functioning
Patient		
<i>Amusement film</i>		
Positive non-target emotions	-0.15*	0.04
Negative non-target emotions	-0.18*	-0.09
<i>Sadness film</i>		
Positive non-target emotions	-0.16*	0.01
Negative non-target emotions	-0.22**	-0.02
<i>Disgust film</i>		
Positive non-target emotions	-0.12	-0.03
Negative non-target emotions	-0.05	-0.06
* $p < 0.05$; ** $p < 0.01$.		

Table 4. Patient experience of positive and negative non-target emotions as predictors for caregiver emotional well-being

	Caregiver emotional well-being					
	amusement film		sadness film		disgust film	
	step 1 β	step 2 β	step 1 β	step 2 β	step 1 β	step 2 β
Patient						
Sex ^a	0.16*	0.18**	0.17**	0.18**	0.16*	0.17*
Age	0.16*	0.17*	0.18**	0.16*	0.17*	0.17**
Disease status ^b	-0.16*	-0.16*	-0.17*	-0.17*	-0.17*	-0.16*
Dementia severity (CDR-box)	-0.16*	-0.13	-0.14 [†]	-0.11	-0.17*	-0.15 [†]
Emotion rating deficit	0.01	0.03	0.04	0.04	-0.003	0.01
Target emotion	0.01	0.01	-0.01	0.01	-0.06	-0.04
Positive non-target emotions	-	-0.05	-	-0.03	-	-0.05
Negative non-target emotions	-	-0.17*	-	-0.15*	-	-0.08
R^2	0.16***	0.19***	0.16***	0.18***	0.16***	0.17***
ΔR^2	0.16***	0.03*	0.16***	0.02 [†]	0.16***	0.01

CDR-box, Clinical Dementia Rating Scale box score. [†] $p < 0.10$; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$. ^a Sex: 1 = female, 0 = male.
^b Disease status: 1 = patients, 0 = healthy participants.

patient diagnosis revealed the same pattern of findings, although the results for the sadness film now only approached significance (amusement film: $\beta = -0.16$, $t = 2.25$, $p = 0.025$; sadness film: $\beta = -0.13$, $t = 1.77$, $p = 0.079$; online suppl. Table 3).

It is worthwhile to note that although the experience of the target emotions was entered as a covariate, it did not predict caregiver emotional well-being in either step of the model for any of the films ($t < 0.87$, $p > 0.38$; Table 4).

Patient Experience of Non-Target Emotions and Caregiver Physical Functioning

As shown in Table 5, after accounting for the covariates, patient experience of non-target emotions did not significantly predict caregiver physical functioning ($t < 1.35$, $p > 0.17$). The additional regression analyses accounting for patient diagnosis revealed similar results ($t < 1.33$, $p > 0.18$; online suppl. Table 4).

Discussion

The present study found that greater experience of negative non-target emotions by patients with neurodegenerative diseases is related to lower emotional well-being in their caregivers. These effects were found for the amusement and sadness films, but not for the disgust film, and were specific to patients' experience of *negative non-target* emotions, but not *positive non-target* emotions or *target* emotions. These effects were also specific to caregiver emotional well-being, but not caregiver physical functioning.

Patient Experience of Negative Non-Target Emotions: The Cost for Caregivers

Subjective emotional experience plays a critical role in facilitating adaptive behaviors and social communication [12, 13]. The experience of negative non-target emotions can be particularly challenging in the interactions between patients and caregivers. Imagine a patient experiencing hostility and anger in response to affectionate behaviors expressed by the caregiver and behaving accordingly. Confronted with this, the caregiver would likely feel misun-

Table 5. Patient experience of positive and negative non-target emotions as predictors for caregiver physical functioning

	Caregiver physical functioning					
	amusement film		sadness film		disgust film	
	step 1 β	step 2 β	step 1 β	step 2 β	step 1 β	step 2 β
Patient						
Sex ^a	0.05	0.05	0.07	0.07	0.07	0.07
Age	-0.13 [†]	-0.11	-0.13 [†]	-0.13 [†]	-0.12 [†]	-0.12 [†]
Disease status ^b	-0.003	-0.01	-0.01	-0.01	-0.01	-0.01
Dementia severity (CDR-box)	-0.12	-0.11	-0.09	-0.09	-0.13	-0.12
Emotion rating deficit	0.06	0.06	-0.02	-0.02	0.04	0.05
Target emotion	<0.001	-0.02	-0.20**	-0.20**	-0.09	-0.08
Positive non-target emotions	–	0.07	–	-0.003	–	-0.02
Negative non-target emotions	–	-0.10	–	-0.005	–	-0.03
R^2	0.03	0.04	0.06 [†]	0.06	0.04	0.04
ΔR^2	0.03	0.01	0.06 [†]	0.00	0.04	0.00

CDR-Box, Clinical Dementia Rating Scale box score. [†] $p < 0.10$; ** $p < 0.01$. ^a Sex: 1 = female, 0 = male. ^b Disease status: 1 = patients, 0 = healthy participants.

derstood and frustrated. Similar events, repeated with increasing frequency as the disease progresses, may erode the quality of the patient-caregiver relationship and lead to declines in caregivers' emotional well-being.

Specificity of Findings

Negative But Not Positive Non-Target Emotional Experience. We found that greater experience of negative, but not positive, non-target emotions was related to lower caregiver emotional well-being. Unexpected negative emotional reactions from patients with neurodegenerative diseases may be particularly difficult for caregivers, who are already experiencing a great deal of stress and burden [2, 3]. This may be further compounded when patients indicate distress and unhappiness in situations where the caregiver might have been expecting positive reactions. Positive emotions calm, soothe, and “undo” the effect of negative emotions [31], and have been linked to building social ties, prosocial behaviors, and better mental health outcomes [32]. For this reason, patients' experience of positive non-target emotions, albeit unexpected, may be less stressful for caregivers.

Target Emotional Experience. Interestingly, we did not find patient experience of target emotions to be associated with caregiver emotional well-being. On the surface, this appears to be inconsistent with findings that emotional blunting or apathy is associated with increased caregiver burden and psychiatric symptoms [33]. However, considering both target and non-target emotions can reveal additional complexities regarding emotional responding. For example, in our previous research, we found that patients with FTD reported less experience of target emotions (which is consistent with emotional blunting), but also greater experience of negative non-target emotions (which is not consistent with emotional blunting) compared to patients with other neurodegenerative diseases (including AD) and HC [17]. In the present study, our findings suggest that caregivers are less affected by patients' decreased experience of target emotions than by their increased experience of negative non-target emotions. These findings have important implications for future research on emotional responding, suggesting that assessing non-target emotions might be particularly useful for distinguishing between

types of neurodegenerative disease and for identifying emotional behaviors in patients that are associated with adverse caregiver outcomes.

Amusement and Sadness Films But Not Disgust. The link between greater negative non-target emotional experience in patients and lower emotional well-being in caregivers was found for the amusement and sadness films, but not for the disgust film. This may reflect the fact that the type of disgust film used in this study elicits a range of emotional responses [17]. For example, watching someone being compelled to eat something revolting can cause viewers to feel anger at the person compelling the action, sad for the person having to comply, or amused at one's own responses. For this reason, non-target emotions in response to disgusting situations may be more expected and less salient, and thus less jarring and disturbing to caregivers than negative non-target emotions in response to amusing or sad situations.

Emotional Well-Being But Not Physical Functioning. The link between greater patient non-target emotional experience and lower caregiver emotional well-being did not extend to caregiver physical functioning. We suspect that the impacts of this problematic patient behavior on caregiver physical health and physical functioning will take longer to develop. For example, in a recently completed 20-year longitudinal study, we found that links between negative emotions and physical health problems in neurologically healthy couples only appeared after more than a decade [34].

Implications

There are a number of implications of these findings. As mentioned earlier, assessments of patient emotional functioning in both research and clinical contexts may benefit from including patient experience of non-target emotions as well as target emotions. Our findings may also help identify caregivers who are at heightened risk for declines in emotional well-being and help identify targets for interventions designed to protect caregivers from the adverse effects of problematic patient behaviors.

Strengths, Limitations, and Future Directions

This is the first study to our knowledge that examined the association between patients' experience of non-target emotions and caregiver emotional well-being. Strengths included: (a) relatively large sample size, (b) heterogeneous sample (a wide range of neurodegenerative diseases were included), (c) generalizability across multiple emotion-eliciting stimuli (i.e., amusement and sadness), and (d) evaluating specificity as to aspects of patient behavior (negative non-target but not positive non-target or target emotions), aspects of caregiver functioning (emotional well-being but not physical functioning), and types of emotion-eliciting stimuli (amusement and sadness but not disgust).

Limitations included: (a) the cross-sectional design limited inferences about the direction of causal influences and (b) other caregiver characteristics that may moderate observed effects (e.g., personality traits [35]) were not examined. Future studies should address these limitations and explore the mechanisms that link patient negative non-target emotional experience to lower caregiver emotional well-being over time.

Conclusion

The present study revealed a previously unstudied patient emotional behavior, greater negative non-target emotional experience, which is related to lower caregiver emotional well-being. Given the increasing rates of neurodegenerative diseases and associated caregiving, there is an urgent need to identify particular factors that influence vulnerability to the

negative effects of caregiving. Aggregating the present findings with our previous findings on the association between visual avoidance in patients and mental health in caregivers [11], we suggest that a comprehensive (e.g., emotion reactivity, regulation, and recognition) and detailed (e.g., target and non-target emotions) assessment of patient emotional functioning will be helpful in developing a more complete understanding of associations between particular patient behaviors and particular adverse caregiver outcomes, which may benefit both the caregivers and patients [4].

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Disclosure Statement

The authors declare no conflict of interest.

References

- Schulz R, Martire LM: Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry* 2004;12:240–249.
- Cuijpers P: Depressive disorders in caregivers of dementia patients: a systematic review. *Aging Mental Health* 2005;9:325–330.
- Joling KJ, van Hout HP, Schellevis FG, van der Horst HE, Scheltens P, Knol DL, van Marwijk HW: Incidence of depression and anxiety in the spouses of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. *Am J Geriatr Psychiatry* 2010;18:146–153.
- Lwi SJ, Ford BQ, Casey JJ, Miller BL, Levenson RW: Poor caregiver mental health predicts mortality of patients with neurodegenerative disease. *Proc Natl Acad Sci USA* 2017;114:7319–7324.
- Gaugler JE, Kane RL, Newcomer R: Resilience and transitions from dementia caregiving. *J Gerontol B Psychol Soc Sci* 2007;62:P38–P44.
- Schulz R, O'Brien AT, Bookwala J, Fleissner K: Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist* 1995;35:771–791.
- Ornstein K, Gaugler JE: The problem with “problem behaviors”: a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. *Int Psychogeriatr* 2012;24:1536–1552.
- Eckart JA, Sturm VE, Miller BL, Levenson RW: Diminished disgust reactivity in behavioral variant frontotemporal dementia. *Neuropsychologia* 2012;50:786–790.
- Goodkind MS, Gyurak A, McCarthy M, Miller BL, Levenson RW: Emotion regulation deficits in frontotemporal lobar degeneration and Alzheimer's disease. *Psychol Aging* 2010;25:30–37.
- Goodkind MS, Sturm VE, Ascher EA, Shdo SM, Miller BL, Rankin KP, Levenson RW: Emotion recognition in frontotemporal dementia and Alzheimer's disease: a new film-based assessment. *Emotion* 2015;15:416.
- Otero M, Levenson RW: Lower visual avoidance in dementia patients associated with greater psychological distress in caregivers. *Dement Geriatr Cogn Disord* 2017;247–258.
- Keltner D, Haidt J: Social functions of emotions at four levels of analysis. *Cogn Emot* 1999;13:505–521.
- Levenson RW: The intrapersonal functions of emotion. *Cogn Emot* 1999;13:481–504.
- Levenson RW: Human emotion: a functional view; in Ekman P, Davidson RJ (eds): *The Nature of Emotion: Fundamental Questions*. New York, Oxford University Press, 1994, pp 123–126.
- Monin JK, Martire LM, Schulz R, Clark MS: Willingness to express emotions to caregiving spouses. *Emotion* 2009;9:101–106.
- Seeley WW, Crawford RK, Zhou J, Miller BL, Greicius MD: Neurodegenerative diseases target large-scale human brain networks. *Neuron* 2009;62:42–52.
- Chen K-H, Lwi SJ, Hua AY, Haase CM, Miller BL, Levenson RW: Increased subjective experience of non-target emotions in patients with frontotemporal dementia and Alzheimer's disease. *Curr Opin Behav Sci* 2017; 77–84.

- 18 Ware JE Jr, Sherbourne CD: The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;30:473–483.
- 19 Litvan I, Agid Y, Calne D, Campbell G, Dubois B, Duvoisin RC, Goetz CG, Golbe LI, Grafman J, Growdon JH, Hallett M, Jankovic J, Quinn NP, Tolosa E, Zee DS: Clinical research criteria for the diagnosis of progressive supranuclear palsy (Steele-Richardson-Olszewski syndrome): report of the NINDS-SPSP international workshop. *Neurology* 1996;47:1–9.
- 20 Armstrong MJ, Litvan I, Lang AE, Bak TH, Bhatia KP, Borroni B, Boxer AL, Dickson DW, Grossman M, Hallett M, Josephs KA, Kertesz A, Lee SE, Miller BL, Reich SG, Riley DE, Tolosa E, Troster AI, Vidailhet M, Weiner WJ: Criteria for the diagnosis of corticobasal degeneration. *Neurology* 2013;80:496–503.
- 21 McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM: Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA work group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. *Neurology* 1984;34:939–944.
- 22 Strong MJ, Grace GM, Freedman M, Lomen-Hoerth C, Woolley S, Goldstein LH, Murphy J, Shoesmith C, Rosenfeld J, Leigh PN, Bruijn L, Ince P, Figlewicz D: Consensus criteria for the diagnosis of frontotemporal cognitive and behavioural syndromes in amyotrophic lateral sclerosis. *Amyotroph Lateral Scler* 2009;10:131–146.
- 23 Rascovsky K, Hodges JR, Knopman D, Mendez MF, Kramer JH, Neuhaus J, et al: Sensitivity of revised diagnostic criteria for the behavioural variant of frontotemporal dementia. *Brain* 2011;134:2456–2477.
- 24 Gorno-Tempini ML, Hillis AE, Weintraub S, Kertesz A, Mendez M, Cappa Se, emsp14, al, Ogar J, Rohrer J, Black S, Boeve BF: Classification of primary progressive aphasia and its variants. *Neurology* 2011;76:1006–1014.
- 25 Levenson RW: Emotion elicitation with neurological patients; in Coan JA, Allen JJB (eds): *Handbook of Emotion Elicitation and Assessment*. New York, Oxford University Press, 2007, pp 158–168.
- 26 Shiota MN, Levenson RW: Turn down the volume or change the channel? Emotional effects of detached versus positive reappraisal. *J Pers Soc Psychol* 2012;103:416–429.
- 27 Gross JJ, Levenson RW: Emotion elicitation using films. *Cogn Emot* 1995;9:87–108.
- 28 Derogatis LR, Unger R: Symptom Checklist-90-Revised. *The Corsini Encyclopedia of Psychology*. Hoboken, Wiley & Sons, Inc, 2010.
- 29 Morris JC: The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology* 1993;43:2412–2414.
- 30 Gross JJ, John OP: Facets of emotional expressivity: three self-report factors and their correlates. *Pers Individ Dif* 1995;19:555–568.
- 31 Fredrickson BL, Levenson RW: Positive emotions speed recovery from the cardiovascular sequelae of negative emotions. *Cogn Emot* 1998;12:191–220.
- 32 Fredrickson BL, Cohn M: Positive emotions; in Lewis MD, Haviland-Jones JM, Barrett LF (eds): *Handbook of Emotions*. New York, Guilford Press, 2007, pp 777–796.
- 33 Terum TM, Andersen JR, Rongve A, Aarsland D, Svendsboe EJ, Testad I: The relationship of specific items on the Neuropsychiatric Inventory to caregiver burden in dementia: a systematic review. *Int J Geriatr Psychiatry* 2017;32:703–717.
- 34 Haase CM, Holley SR, Bloch L, Verstaen A, Levenson RW: Interpersonal emotional behaviors and physical health: a 20-year longitudinal study of long-term married couples. *Emotion* 2016;16:965–977.
- 35 Hooker K, Frazier LD, Monahan DJ: Personality and coping among caregivers of spouses with dementia. *Gerontologist* 1994;34:386–392.